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ABSTRACT

This report discusses policies and practices for family-directed child evaluation and assessment under the Individuals with Disabilities Education Act (IDEA). The scope of the report includes practices across the early childhood spectrum, from birth through 5 years. Commonly used terminology is defined. Issues discussed include: the primacy of families with respect to their children, cultural and linguistic diversity, the use of technological advances, and information about a child's health status and needs. Brief recommendations for policymakers are given and lists of the U.S. Department of Education's Early Education Program for Children with Disabilities (EEPCD) projects, as well as other resources, are included. (SG)

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by Carol Berman and Evelyn Shaw

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NEC·TAS
National Early Childhood Technical Assistance System
Chapel Hill, North Carolina

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The EEPCD project staff interviewed for this paper were:

- Diane Bricker of AEPS Linked System of Assessment, Intervention and Evaluation for Early Intervention, Eugene, Oregon;
- Angela G. Deal of Family, Infant, and Preschool Program (FIPP), Morganton, North Carolina;
- Corinne Garland of Trans/Team Outreach at Child Development Resources (CDR), Lightfoot, Virginia;
- Pat Haley and Janet Valluzzi of Medically Fragile Inservice for Related Services Team (M-First), Portland, Oregon, and Seattle, Washington;
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- Barbara Jackson and Joanie Dinsmore of Project Continuity Outreach, Omaha, Nebraska; and
- Linda Kjerland of Project Dakota, Eagan, Minnesota.

Contact information and product listings for each project are included in the resource section at the end of this paper.

The following parents contributed to this study:

- Lisa and Roger Bailey, of Eugene, Oregon;
- Denise Booth, of Pittsfield, Illinois;
- Renee Dulin, of Troutman, North Carolina;
- Ken and Lynn Gillies, of Eagan, Minnesota;
- John and Teresa Guthman, of St. Paul, Minnesota;
- Kelly Perron, of Springfield, Oregon;
- Barbie Perry, of Toano, Virginia;
- Michael and Nelda Thompson, of Mooresville, North Carolina; and
- Glenda Witt, of Williamsburg, Virginia.

All were knowledgeable, generous of their time, and immensely interested in sharing their insights. Their contributions greatly enriched our thinking and understanding by providing tangible experiences and recommendations.

PREFACE

The Individuals with Disabilities Education Act (IDEA) provides grants to states and jurisdictions to support the planning of service systems and the delivery of services, including evaluation and assessment, for young children who have or are at risk for developing disabling conditions. Funds are provided through the Infants and Toddlers Program (known as Part H of IDEA) for services to children from birth through 2 years of age, and through the Preschool Program (known as Section 619 of IDEA) for services to children 3 through 5 years of age.

To assist states and jurisdictions in meeting the challenges of implementing IDEA, the U.S. Department of Education's Early Education Program for Children with Disabilities (EEPCD) sponsors a wide variety of research institutes and model demonstration, inservice training, data system, and outreach projects. Outreach projects specifically are funded to assist states in identifying and implementing system and service delivery models, model components, and personnel training approaches.

The National Early Childhood Technical Assistance System (NEC*TAS) supports the implementation of IDEA in its role as a national technical assistance provider to state, jurisdictional, and EEPCD project personnel. Part of its mission is to facilitate linkages between states and jurisdictions and EEPCD projects. NEC*TAS publications are one vehicle for bringing information from EEPCD projects — in this case, outreach projects — to state policy makers and program coordinators.

About This Report

This report discusses practices which families and program staff working in EEPCD projects believe contribute to quality family-directed child evaluations and assessments. These practices take into account the primacy of families with respect to their children, cultural and linguistic diversity, the use of technological advances, and information about a child's health status and needs.

A team of NEC*TAS staff developed this report to help state and EEPCD project personnel learn from one another about family-directed evaluations and assessments. Several EEPCD outreach projects were selected to be interviewed for the report because of their proven models and dissemination responsibility. Questions were reviewed by the team, who then paired off to interview project personnel and parents known to these projects. The principal authors prepared the

report, which was then reviewed by the team and by those who had been interviewed.

INTRODUCTION

The first experience of a family with a child who may need early intervention services typically involves a process of identification, evaluation, and assessment, in which the need for services is established and defined. Ongoing evaluation and assessment are opportunities to reveal the child's strengths and developmental needs and the family's resources and priorities, and help to guide the direction of intervention. These opportunities are highly significant to the family and to service providers. Depending on the program and on the degree of a child's disability, the initial evaluation to determine whether the child qualifies for services and subsequent re-evaluations for that purpose may be seen as rites of passage into early intervention or as threats to eligibility. The degree to which the family is active in the evaluation and assessment processes is likely to influence the child's performance, the extent of follow-up, and the relevance of the evaluation or assessment in guiding the child's developmental program.

This report discusses policies and practices for family-directed child evaluation and assessment under IDEA. Because many family-directed practices originated in programs for infants and toddlers and because language emphasizing family roles and supports appears throughout Part H, the report may appear to emphasize Part H policies and practices over those for the Section 619 population. However, the scope of the report includes practices across the early childhood age spectrum, birth through 5 years. The report defines commonly used terminology and identifies issues and recommended approaches for evaluation and assessment processes. Following a summary of characteristics of successful child evaluation and assessment and brief recommendations for policymakers, the report concludes with lists of project and other resources.

Definitions

"Family-Directed"

As the NEC*TAS team began interviewing parents and professionals for this paper, it quickly became aware that many terms are used to describe the family's involvement in the evaluation or assessment process. The terms "family focused," "family friendly," "family driven," "family directed," and "family guided" tend to be used interchangeably by some people, and used with specific meaning by others. All of these terms convey to some degree the general philosophy of family-centered care, which recognizes the family's constant, central role in the child's life and places family priorities and values over those of the professional or the agency. Although the differences in terminology may

appear to be minor, each term does suggest a difference in emphasis and in the family's role.

The NEC*TAS team elected to use the term "family directed" because it suggests an active role for the family throughout the evaluation and assessment processes. Parents and project staff whom we interviewed emphasized that if professionals relate to the family in a way that is friendly and supportive, but fail to allow the family to determine the outcomes it desires, then evaluations and assessments will fall far short of meeting the needs of the child, of the family, and, ultimately, of the service providers. Although it is important that evaluations and assessments be conducted as early as possible in the child's life by personnel who are knowledgeable about appropriate resources, effective evaluation and assessment practices also are respectful of parents and the primacy of their role in their child's care and education. The term "family directed" offers a suitable emphasis of appropriate parent participation in the process.

"Evaluation" and "Assessment"

The term "evaluation" under Part H of IDEA generally means the determination of eligibility, whereas "assessment" refers to the ongoing process of determining the child's and family's strengths and needs. Regulations for Part H (Department of Education, 1993; 34 CFR §303) define evaluation and assessment as follows:

> §303.322(b)(1) *Evaluation* means the procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility under this part, consistent with the definition of "infants and toddlers with disabilities" in §303.16, including determining the status of the child in each of the developmental areas in paragraph (c)(3)(ii) of this section.
>
> (2) *Assessment* means the ongoing procedures used by appropriate qualified personnel throughout the period of a child's eligibility to identify–
>
> (i) the child's unique strengths and needs and the services appropriate to meet those needs; and
>
> (ii) The resources, priorities, and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability. (p. 40971)

An easy way to remember the distinction made within the Part H regulations is that the terms "evaluation" and "eligibility" both start with the letter "e." Despite their distinct meanings under Part H, the terms evaluation and assessment tend to be used interchangeably by parents and practitioners in the field.

The term "assessment" does not appear in the regulations for Part B of IDEA (Department of Education, 1992); "evaluation" is used instead. Under Part B, which includes Section 619, evaluation focuses on the educational needs of the child and requires that "no single procedure is used as the sole criterion for determining an appropriate educational program for a child" and "the evaluation is made by a multidisciplinary team or group of persons" (see 34 CFR §§300.532(d) and (e)). When interpreting evaluation data in making placement decisions, each public agency shall "draw upon information from a variety of sources, including aptitude and achievement tests, teacher recommendations, physical condition, social or cultural background, and adaptive behavior" and "ensure that information obtained from all of these sources is documented and carefully considered" (see 34 CFR §§300.533(a)(1) and (2)).

State Part H and Part B-Section 619 programs address family involvement in evaluation and assessment processes, but with different emphases. Under Part H regulations, child assessment includes identification of the "resources, priorities, and concerns of the family" (see 34 CFR §303.322 (b)(2)(ii)). Although parents are not specifically mentioned in the Part B regulations, many states have recognized the important contributions and primary decision-making role of parents throughout the process. Many state guidelines for evaluating preschool children — such as those from Arizona, Colorado, Ohio, Pennsylvania, Rhode Island, and Vermont — do encourage multidisciplinary evaluation teams to involve parents as contributing members.

"Family Assessment"

"Family assessment" is a term that often is misunderstood and that does not convey the collaborative working relationships between families and professionals that are at the heart of family-directed services. Family assessment is defined as "family-directed and designed to determine the resources, priorities, and concerns of the family related to enhancing the development of the child." Family assessment is voluntary and, if carried out, must be "based on information provided by the family through a personal interview" (see 34 CFR §303.322(d)). Families need to be able to define themselves; a family often extends beyond parents and siblings and may include elders, spiritual leaders, and extended family members. Linda Kjerland of Project Dakota, in Eagan, Minnesota, who prefers the term "family information gathering" to "family assessment," emphasized that early intervention professionals are not being asked to intrude upon the privacy of families, but are charged with providing opportunities for families to choose to share the challenges for which they want help and support.

In attempting to respect the individuality of families and the differences among them, a system should not be set up which meets the requirement for family-directed assessments by simply adding a form for families to complete. Linda Kjerland put it this way: "The worst mistake we can make is to think we have met the intent of the law by having families fill out a form instead of shaping the whole process." Project Dakota has developed questionnaires and other reminders to practitioners to be responsive to the family at every step.

CHARACTERISTICS OF FAMILY-DIRECTED CHILD EVALUATIONS AND ASSESSMENTS

Throughout the interviews with EEPCD project personnel and parents, a number of key concepts emerged relating to assessment and evaluation practices, many of which have policy and practice implications. These are presented below, grouped in four issue areas: (1) family issues; (2) process issues; (3) personnel preparation issues; and (4) service system issues.

Family Issues

Value Parents as Experts.

Programs with family-directed assessments ensure that parents have input at every step. An environment is created in which parents are made to feel comfortable about contributing as important team members. At Child Development Resources (CDR), Lightfoot, Virginia, assessment reports are stamped "draft" and mailed to parents for their review and comment. In this way, the program emphasizes that input still is being sought, especially when a report has been typed for readability and may appear to be more final than intended. Roger and Lisa Bailey, parents from Eugene, Oregon, told us why they were satisfied with services at the AEPS Linked System of Assessment, Intervention and Evaluation for Early Intervention Project (AEPS) headed by Diane Bricker: "Testers tell us how they are going to test, what they will be looking for, information about the test, what to *expect*. They did their own testing, made their own observations, and asked us what [our child] did at home. There is no way one individual can figure out a child. We feel it's very important to take information from parents." Ken Gillies, a parent from Eagan, Minnesota, whose child was seen at Project Dakota, said: "The professionals in any family's case need to be the *listener*. It's hard for people in our structure of society to take on that role. Unless you have gleaned significant information from the family, you aren't in a position to offer any opinion."

Angela Deal, of the Family, Infant, and Preschool Program (FIPP), Morganton, North Carolina, acknowledged that the purpose of and people involved in evaluation for preschool children may be different than that for infants and toddlers, but the process still can be driven by the families' perspectives and priorities. Families want their children to be successful in preschool. John Guthman, a parent from St. Paul, Minnesota, emphasized that if important skills are needed for success in the preschool setting, then the assessment team should

draw on parents' experience and knowledge of their child at home to find out what the child's abilities are in relation to those skills.

Respect Individual Differences and Values and Families' Styles of Involvement.

Families vary considerably as to the role and amount of control they want to assume in evaluation and assessment, and throughout early intervention and preschool. Some parents may want to be more active than others in making decisions and in coordinating services. John Guthman told us: "We asked questions. Not all families do, especially for the initial assessment when they don't know what to expect. They are not in a comfortable place, or they may [expect to] hear bad news."

Even if parents choose to do no more than observe, the process of engaging them as "active" observers still is a step in articulating the *family's* desired outcome for the child. Glenda Witt, a parent from Williamsburg, Virginia, who experienced family-directed assessments at CDR, put it this way: "If the family doesn't feel involved, nothing will change." Angela Deal, of the FIPP project, concurred: "What happens must be dictated by the comfort level of the family and how and what they choose. Even as an observer, what is being done is based on the family's outcomes."

Diane Bricker, of the AEPS project, emphasized that an active family role does not mean abdication by professionals of their responsibilities. It is imperative that professionals help families shape a reasonable course of action by suggesting and describing appropriate options.

As in any partnership, parents have a responsibility to work in partnership with practitioners during the evaluation and assessment processes. For example, parents can help practitioners by communicating their expectations for their child, by observing and commenting on their child's performance during assessment, and by asking questions about aspects of the evaluation and assessment that are unclear to them. A publication by the ERIC Clearinghouse (1994), *Rights and Responsibilities of Parents of Children with Disabilities*, although primarily directed at parents of children enrolled in a program, offers guidance to parents about their rights and responsibilities in the special education process, including evaluations.

By and large, the professionals and parents we interviewed strongly favored a very active role for families, one in which they participated in every aspect of evaluation and assessment.

Encourage the Presence and Participation of Parents and Other Family Members.

It is inappropriate to evaluate a young child without the presence of someone who knows the child very well, particularly if eligibility for services is being considered. The person who knows the child best may be a parent or it may be a grandmother, aunt, uncle, or neighbor. Most parents want and need to be present during evaluation and assessment, particularly when the child is an infant. Denise Booth, a Pittsfield, Illinois, parent, liked having a sibling included in her child's assessment and appreciated the benefits of using a videotape to capture the interaction between the children.

The need to include families has implications for assessments performed at child care programs and other community settings. For example, assessments should be arranged at times and settings which are convenient for families and for professionals. Renee Dulin, a parent from Troutman, North Carolina, whose child receives services from the FIPP project, spoke of the need for a parent presence and for preliminary home visits: "A family with a special needs child spends a lot of time with [personnel who are] strangers. It is so important for the parents as well as for the child to have a familiar face present on assessment day. Personally, I can't imagine having to endure an assessment for a child younger than school age without being allowed to be present. I would not allow my child to be put into a room with strangers and be expected to perform (optimally). An assessment of this type is unfair to the child and to the team members."

Process Issues

Appreciate the Process Leading to a Plan.

Families have the right to be part of planning an assessment process that culminates in a report that is honest, that presents what the team knows, and that steers them toward solutions and resources. Ken Gillies thought the term "discover" might better describe what the process should be. He said: "When I hear the word 'discover' sunshine pops into my mind. But 'assessment' and 'evaluation' – you think of piles of paper and raised eyebrows. That's not the purpose. It's to get good things for our child." John and Teresa Guthman described assessment as "part of an ongoing process of setting goals."

The assessment that recognizes a linked continuum of services helps define needed services that will benefit the child and family. Diane Bricker, of the AEPS project, offered this description of the linked continuum:

Screening, as a first level, is an economical strategy for determining which children need further evaluation. Not all children are screened; some are evaluated or assessed as a first step in the process of early intervention. Screening is one entry route into the early intervention program.

The *evaluation*, as a second level, leads to a possible diagnosis; to a determination of eligibility; to a description of the nature of any problem; and to an interim placement, if necessary.

Assessment, as the third level, determines therapeutically appropriate intervention. If a child is enrolled in early intervention services, assessment should be continuous. It can be carried out at varying levels of formality; sometimes it is a structured interview or observation, or it may occur during the intervention process.

An important aspect of the linked continuum of services is that it is far more than a label, a quotient, or a score. The emphasis should be on child and family priorities and should lead to reasonable educational and therapeutic plans and outcomes.

Value the Importance and Impact of Every Interaction.

Every interaction that occurs between parents and professionals is an important event. The NEC*TAS team affirmed in our interviews that those contacts can be warm, exhilarating, fearsome, or devastating. Parents often dread an experience in which they feel their child and, for that matter, they are being judged. Evaluations and assessments by professionals or teams who fail to express any positive findings can be demoralizing and can undermine relationships between parents, between parent and child, and between parent and professional.

Attention should be paid to nonverbal and situational cues. Professionals' behaviors – gestures, smiles, the way they hold a child, openness, their preparedness for the child and family, even the way the appointment is made – can be as illuminating as what is said. Barbie Perry, of Toano, Virginia, whose child had been followed by CDR, described a family-directed experience: "[My child's] name was on the paperwork when I got there. I knew this was where she was supposed to be."

Lynn Gillies emphasized that "information shared with families after an assessment should start with the positives and then move to areas of concern." Glenda Witt said that "the report should make you feel good about your child and always leave you on an up note. Their [CDR's] report was very positive and highlighted skills. [We] felt that the professionals were on our side. Reports should emphasize what the child knows, not just what he does not do."

Provide Necessary Information at the Most Opportune Time.

The goals and purposes of assessment should be articulated from the beginning, before the actual assessment, so parents know what to expect. This pre-assessment communication also can help allay fears.

Nelda Thompson, a parent from Mooresville, North Carolina, who was satisfied with family-directed assessments at FIPP, talked about the benefit of periodically checking with parents to see what they need in terms of materials or information. Neither written materials without follow-up, nor discussion without written materials, is sufficient. To the extent possible, materials should be individually tailored for a particular family. Language differences and literacy levels always should be considered.

Parents want access to the same information that is available to the professionals on the team. Information about test scores or a diagnosis should be provided with explanations. Families should be encouraged to obtain, keep, and organize copies of their child's records for their own reference and to facilitate care. In order for parents to be able to fully participate in team decisions, fact and opinion should be clearly distinguished and all available options presented. Roger and Lisa Bailey said: "Parents may not know what questions to ask. It helped us when someone said, 'These are the options' and 'Here's what I think I see' and fed us questions. . . . It's important to have a multidisciplinary team assess the child. You get an amazingly complete and accurate picture, and it helps you to come up with appropriate goals."

Parent-to-parent support was particularly helpful to some of the parents we interviewed, including Ken and Lynn Gillies, who suggested that programs may need to overcome the attitude of "we know what's best" to connect parents to someone who has "been there."

Allow for Flexibility in Location, Timing, and Personnel.

Virtually every family member who talked about good evaluation and assessment experiences had been contacted before the assessment, perhaps through a home visit. Because they had been prepared beforehand, they knew what to expect. Parents of infants, toddlers, and preschool children felt that home visits were important and should precede a formal assessment. In contrast, parents who were dissatisfied with evaluation and assessment procedures, felt that they had little say in the arrangements. The system needs to allow for an evaluation or assessment to be conducted in a setting and at a time that works best for a family and child. Although some families are comfortable with professionals coming to

their homes, other parents may prefer to meet at the program site or other neutral setting.

Renee Dulin said: "Trust is very important. You can't do that 'til you are comfortable. . . . If it was nap time, nursing time, whatever [my child's] needs were, they came first." In contrast to her family-directed evaluation at the AEPS program, Oregon parent Kelly Perron, characterized a less positive experience elsewhere: "We were there from 8:30 a.m. until 12:15 p.m. We had no preparation. I didn't bring a snack. As a result, I had a cranky, tired, and hungry baby."

"Let families have a choice," said Ken Gillies. "A difficult piece of the assessment puzzle is assigning individuals to an assessment team. Perhaps one individual does not 'click' with the family; the family needs to express to the professional team member that they are not comfortable and should be able to ask for a change in a team member. Flexibility in scheduling is important. Early mornings or evenings are usually best for families."

Corinne Garland, of the Trans/Team Outreach Project housed at CDR, emphasized flexibility as a cornerstone of family-directed assessments. She noted that families differ widely, and that every assessment team may require a different level of preparation, composition, and level of support to engage parents as active participants.Her program often uses transdisciplinary arena assessments. A transdisciplinary arena assessment is a planned observation process which typically involves *a facilitator*, who serves as the primary interactor/contact with the child and family during the assessment process; *a coach*, who supports the facilitator, provides cues for missed items, or reflects on what could be done to enhance the assessment; *observers*, who serve as multidisciplinary "eyes and ears" and contribute expertise from a variety of backgrounds and training; and, *parent(s)*, who serve as additional evaluators, observers, and contributors.

Recognize the Limitations of Current Instruments and Encourage the Use of Informal Measures.

Whether we use standardized or informal measures or both, we should acknowledge the shortcomings of current instruments. When we use formal measures, we need to be fully familiar with them and choose only those that are appropriate for the language and culture of the child and family. Further guidance on these concepts is available in other NEC*TAS reports (see Biro, Daulton, & Szanton, 1991; Meisels & Provence, 1989; Shackelford, 1994).

Corinne Garland emphasized that we may be asking the wrong questions when we restrict ourselves to the parameters of standardized instruments. Important questions that should be asked include: What is the child capable of doing? What does the family tell us about this child? Would assistive technology help in drawing out optimal performance? What kinds of help might this child need? Diane Bricker, of the AEPS Project, commented: "One of the problems with assessments in general is the diagnostic label. We have conveyed to a lot of families that a label, a score, a diagnostic quotient is a 'something.' What is important are the child's needs, reasonable educational and therapeutic goals, and family outcomes."

Common themes expressed in our interviews were the need to recognize and respect the accuracy of parent reporting, the importance of verifying with families the information gleaned from observation of play, and the difficulty in eliciting a representative sample of a young child's behavior. We need to check with parents to know whether or not we saw a representative sample of the child's abilities. Consideration of the child's health, medication, level of fatigue, and other factors is important, and family members are likely to be the best informants about the caliber of a child's performance.

One method of assuring that staff and family perceptions are blended is the use of a collaborative description of the child. Project Dakota adapted transdisciplinary post-assessment discussion methodology and integrated elements of the McGill Action Planning System (MAPS) (Pearpoint & Forest, 1992) into a functional team activity. In this collaborative description, families and staff cite child abilities, interests, and motivators; things to celebrate; as well as concerns, frustrations, worries, and desired next steps. Through this partnership, families and professionals can clarify what parents expect to gain and whether the plans that are developed are consistent with family priorities and goals. In the original MAPS process – which was designed to plan for the inclusion of children with disabilities in regular classrooms and activities – the child, family members, friends, and professionals meet as a group with a facilitator and generate ideas around key questions, such as "What would the child's ideal day at school look like?" and "What must be done to make it happen?" Lisa Gillies spoke with affection of an Individualized Family Service Plan (IFSP) meeting convened in her living room, in which neighbors were involved in helping to design her child's program.

Integrate Health Evaluations Into the Total Evaluation.

Information about a child's medical diagnosis and health status are of vital interest to early intervention and preschool programs, including how health status

influences the child's development and what, if any, restrictions health status places on the child. Information from a health evaluation can enable staff to design more appropriate programming for a child and may uncover a physical basis for learning difficulties or lack of progress. Such information also may be necessary to ensure the child's safety. Likewise, health professionals can benefit from the information from developmental assessments.

Our interviews with Barbara Jackson and Joan Dinsmore, of Project Continuity, and with Pat Haley and Jan Valluzzi, of the M-FIRST Project, emphasized the importance of integrating health assessments into the evaluation process for children with special health care needs, as well as for children who do not have medical complications. Child assessment must include an assessment of health needs. Information from health evaluations should be interpreted and integrated in the planning of a child's daily program.

Project Continuity staff members emphasized the importance of communicating information from health care professionals to other professionals. Similarly, Rodd Hedlund, of the NICU Follow-Through Project, stressed the importance of making developmental assessment information available to medical and health personnel in hospital settings. Staff from all three projects emphasized the importance of regular communication between health care providers and early intervention and preschool programs and suggested the following strategies:

- providing information in a written format, free of jargon;
- incorporating health status information in the IFSP and the Individualized Education Program (IEP);
- encouraging health care providers' participation in the evaluation and IFSP process;
- pursuing mechanisms to reimburse medical and health personnel for their participation in these processes; and,
- planning to implement and integrate health interventions in the educational setting.

Benefit From Technology in Evaluation and Assessment.

Technology can make things easier for many people, and for people with disabilities, it often makes things possible. Patti Hutinger, Carol Schneider, and Linda Robinson, from Project ACTT, emphasized that assistive technology (AT) should be an inseparable part of the assessment and evaluation processes, both in terms of obtaining optimal information about the child and in planning appropriate interventions. In the same way that the concerns and priorities of

family members cannot be an "add-on," assistive technology should be a standard consideration for young children with moderate to severe disabilities in developing their IFSP or IEP. Indeed, for some children with severe disabilities, technology may be the *only* means by which their abilities can be accurately assessed and by which they can reach their potential.

The range of assistive technology is wide. Although factors related to its use are complex (such as a child's mobility and the length of time it takes to learn to use a device or system), many AT needs are met with simple adaptations and often low-cost solutions. Attitudinal, personnel, and finance issues associated with advances in technology affect evaluation and assessment processes. These issues include: overcoming "tech-phobia"; system-wide awareness of resources; and monetary allocations for specific devices, repairs, adaptations, on-going technical assistance, and training for children, families, and personnel. Early intervention and preschool personnel who work in settings that lack the technology necessary for evaluations and assessments need to learn how to access AT, how to ensure timeliness while doing so, and advocate for acquiring the appropriate technology in their setting.

Families most often are the initiators of and advocates for technology assessment and intervention. ACTT staff confirm that the majority of referrals for AT assessment come from families. Denise Booth said: "Technology will open the door for my child."

Anticipate and Plan for Transition.

Home visits conducted prior to a child's first assessment is a transition process that helps allay parents' concerns and fears and helps them understand what to expect. This can occur at any age in the process of service delivery.

An eligibility determination process is particularly significant for families of children whose eligibility is borderline, especially at age 3 years when making the transition from Part H services to preschool services. Although it is desirable to offer a "seamless system" of services for children to move from one program to another, in practice this is not always the case. The transition from Part H to Part B services, or from Part H to some other community-based service system, can be especially difficult if there are different eligibility criteria, or if there is a conflict between what professionals see as the needed services and what the parents believe to be necessary and desirable for their child.

Lynn Gillies, who has worked with other Minnesota families, pointed out that all transitions are difficult. However, the experience at transition is not always

unfavorable, and families are best served by evaluation and assessment experiences that aid the transfer of records (with the parents' knowledge and approval), incorporate visits from personnel, and result in an uncomplicated entry to new services.

Our interviews highlighted some of the problems associated with evaluation and assessment at the time of transition. Glenda Witt related that "parents don't get as much attention in public school" settings as they do at CDR. She did appreciate, however, that the preschool accepted the last evaluation from CDR so that the evaluation process did not have to be repeated. Barbie Perry's experience with transition to a preschool program also contrasted unfavorably with her experience at CDR. She said: "The preschool program did not let me know what to expect. . . . We did not understand the process for the transition placement. No one explained what would happen. We did not know how long it would take – paperwork was not at the school, the teacher was not present for the evaluation, and we were not welcomed to the program."

Transition planning conferences, in which families are actively involved in decision making, are an appropriate and necessary course of action in order to ease such transitions.

Personnel Preparation Issues

Recognize the Importance of Personnel Qualifications.

The person who conducts the assessment should be the one who knows the child best, and should be well trained and experienced. Professionals' skills need to be fine tuned so that they can change with the evolution of the team and adapt to the nature of families. Personnel preparation for early intervention work requires a myriad of experiences. Training should equip professionals:

- to work with young children and their families;
- to work with teams that include many discipline and agency perspectives;
- to understand and appreciate family-centered, culturally appropriate approaches;
- to be knowledgeable and skilled in the use of instruments and to know when to apply clinical judgment; and
- to understand how to access community resources, including services for children and families, technology, and technology training.

The parents we interviewed were attuned to the level of experience of personnel, and it was important to them. In one instance reported to us, a preschool professional was so inexperienced in assessment practices that the parent, Barbie Perry, took matters into her own hands and showed the professional which toys to use and what to do with them. "She didn't know how to pick up babies. . . . I bared my child's soul to a total stranger. We wanted to learn from this. We wanted someone with experience." In contrast, she described a better experience: "In the hands of trained professionals at CDR – they were prepared and knew what they were doing – . . . I knew the assessment would be fine."

A family's earliest contact with professionals tends to be with health professionals, including nurses, physicians (particularly general practitioners and pediatricians), and local health department personnel. Those who have early contact with a child with disabling conditions need to be aware of the resources available to families. This is particularly critical in remote areas where there are likely to be few, if any, community providers. Denise Booth stated that staff, who provided an assessment far from her home, directed her to services in her own community which she had not known were available.

Ongoing developments in technology that can aid evaluation and assessment have amplified the need for personnel training. Family members also play a key role in increasing awareness of these training needs. Training models and strategies should be designed to take advantage of the expertise of parents and of professionals in the areas of allied health, technology, and early childhood development. An all too common story is that of a child's communication board sitting in the corner of the closet because personnel were not trained to use it. Program administrators should be aware of the benefits of technology and should support training for direct service providers. Even small increases in awareness can be enlightening. Denise Booth quoted a school system administrator who said, "This assessment gave me a whole new picture of what your daughter can do!"

Respect Individual Differences, Values, and Preferences.

Enlightened pre- and inservice training program staff recognize the significance of understanding and respecting cultural differences when working with families. According to Helen Hammond and Lawrence Ingalls, of Project Vision, unless professionals understand and acknowledge their own values and biases, judgmental attitudes and prejudices can interfere with family-directed assessment and evaluation processes. Thus, providers of pre- and inservice training in evaluation and assessment should address this important aspect of interactions between parents and professionals.

Not everyone shares the same values about what constitutes appropriate child development. Some of the milestones that professionals have come to regard as universal, based on standardized instruments and child development literature, may conflict with what some families expect and want for their child.

If a family does not speak English well or at all, the program needs to acquire the services of an interpreter who understands both language and cultural cues. This individual needs to understand the level of information that is being transmitted; for example, if health or medical information is being discussed, some familiarity with the terminology is needed in order to translate appropriately. An understanding of the appropriate and desired level of confidentiality of information also is important. Although it may be convenient to involve a client's neighbor as an interpreter, this may be inappropriate if the family wants to maintain its privacy in the subject area. Each program should consider adopting guidelines for working with interpreters in evaluation and assessment.

Materials about the program, evaluation and assessment procedures, and, particularly, informed consent notices should be available in the native language of the program's client population. Programs that are responsive to cultural differences focus on conducting thorough assessments and evaluations, rather than on developing a list of traits for a given population. Doing so acknowledges the dynamic nature of culture and its influences in our lives.

Service System Issues

Consider Cost in Relation to Benefit.

Angela Deal, of the FIPP project, pointed out that it is penny-wise and pound-foolish to try to economize by not taking time to understand the family's questions and their hopes for their child through assessment and early intervention. Without family buy-in, teams of professionals may spend time and dollars working toward outcomes that are less likely to be attained or less meaningful to the family. This problem was illustrated by Michael and Nelda Thompson's contrasting a greatly valued experience at FIPP with one that had been frustrating: "In [one] evaluation, we had no idea what was in store for us. . . . They told us what we already knew. . . . The *reason* for the evaluation needs to be understood. . . . FIPP was a godsend to us. . . . Linda came to our house and established rapport. She was there at the center. Everyone was tuned in. The team watched him play, eat lunch, and be himself, instead of making him perform."

There may be increased costs to assessment when processes are family directed, associated with the need for flexibility on the part of professionals in conducting

evaluations and assessments that will elicit the child's optimal performance and the family's questions, expectations, and hopes for their child. In order to make evaluation and assessment convenient, informative, and supportive of the family-child relationship, such costs may involve staff travel, altered hours of operation, and other means of adapting to family needs. Such expenditures are relatively modest, yet immensely important (Barnett & Escobar, 1990).

Lisa Gillies (1990) wrote about the importance and economy of considering the family's priorities and needs. She likened parents' involvement in the development of an IFSP to being involved in the design of a blueprint for a family home. Just as floor plan changes are costly when a builder constructs a house "on spec," in her experience it is even more important to build early intervention plans around each family's goals, priorities, and resources, so that efforts are likely to have maximum payoff.

Have Realistic Expectations for Policies and Monitor Their Implementation.

Just because those who write law and regulations *want* something to happen in practice, does not mean that the practice will actually occur. It is not always possible to control through written policy the experience at the grassroots level. Parents provide a reality check for which there can be no substitute. Hence, a forum, perhaps through state and local interagency coordinating councils, should be available for parents to provide information about their experiences at the federal, state, and local levels.

It was obvious from our interviews with parents that evaluations and assessments are not always family directed. Nelda Thompson, who contrasted her evaluation at FIPP with an experience she characterized as "at the bottom," was aware that family-directed practices are not yet universal. In contrast to what she believed she could expect on the basis of laws and policies she had seen, the evaluation's purpose, in her view, was not for the family, but rather to satisfy the program's own need to fill in some numbers. She needed encouragement and received none. She needed emotional support and got none. Professionals in the program did not believe her personal reports. They did not respect her knowledge. She felt defensive about her child. She saw no purpose in the evaluation and assessment.

Our interviews confirmed that there is wide variation in practice, even within a community. This variation serves as a goal for parents, practitioners, and policymakers to encourage family-directed evaluation and assessment in all programs.

Negotiate Conflicting Opinions.

The outcomes of an evaluation and assessment should be a common definition of any problems and common expectations of the course of assessment and treatment. However, team members may disagree about recommended services or some other aspect of the assessment or plan. Whether the difference of opinion is among staff, or between staff and parents, it is important to come to agreement quickly, in order to avoid delaying needed intervention. This may require negotiation among the team. Policymakers should develop a system that values the needs of parents, respects the knowledge of the entire team (including parents), and recognizes that resources are finite.

Professionals and parents we interviewed indicated that families do not want to "drive" themselves through a process or receive services that are unnecessary. They do not want to spend more time in evaluation, assessment, or programs than their child needs. It is important that teams strive for consensus about service needs; this consensus is most likely to occur when families have participated in each step of the process.

Denise Booth emphasized that she wanted her views valued, but that she also respected those of the professionals. She said, "Consider my opinion, and if we see things differently, we can discuss it." Parents emphasized the importance of listening and valuing parents' knowledge, expertise, concerns, and goals for their child.

In acknowledging resource limitations, state policymakers may find it useful to develop guidelines that offer direction about the nature of appropriate treatment, such as the process required for reaching decisions about an IFSP. If such guidelines are developed, flexibility to accommodate the priorities of each child and family and to accommodate diversity across neighborhoods and cultures should be incorporated. It is clear that no formula for frequency and duration of services will apply to all young children and families, just as no universal interventions exist that are appropriate for all.

RECOMMENDATIONS FOR POLICYMAKERS

Through interviews, selected EEPCD project directors and parents of young children with disabilities shared their thoughts about the characteristics of successful, family-directed child evaluations and assessments. These are summarized below in Table 1.

Table 1

CHARACTERISTICS OF FAMILY-DIRECTED CHILD EVALUATION AND ASSESSMENT

Family Issues

- Value Parents as Experts.
- Respect Individual Differences and Values and Families' Styles of Involvement.
- Encourage the Presence and Participation of Parents and Other Family Members.

Process Issues

- Appreciate the Process Leading to a Plan.
- Value the Importance and Impact of Every Interaction.
- Provide Necessary Information at the Most Opportune Time.
- Allow for Flexibility in Location, Timing, and Personnel.
- Recognize the Limitations of Current Instruments and Encourage the Use of Informal Measures.
- Integrate Health Evaluations Into the Total Evaluation.
- Benefit From Technology in Evaluation and Assessment.
- Anticipate and Plan for Transition.

Personnel Preparation Issues

- Recognize the Importance of Personnel Qualifications.
- Respect Individual Differences, Values, and Preferences.

Service System Issues

- Consider Cost in Relation to Benefit.
- Have Realistic Expectations for Policies and Monitor Their Implementation.
- Negotiate Conflicting Opinions.

Throughout the interviews, the following overarching recommendations for those who legislate and administer policy were articulated:

- Be realistic about what happens once a law is written. Policymakers need to remain vigilant about a law as it is applied. The leap from policy to practice is made more difficult when interpretations and nuances are added to legislation or regulation, which then take on a life of their own. By providing clear guidelines and holding forums recurrently about the *intent* of the law, policymakers will provide the direction that administrators, service providers, advocates, and families need.
- Seek the advice of the various cultural communities' leaders on how to increase and sustain family involvement.
- Listen to parents. Parents and other family members provide a reality check for which there can be no substitute.
- Appreciate the significance of family-directed approaches and support the costs associated with enacting the spirit as well as the letter of IDEA and other legislation. If, in listening to families, it is determined by that evaluations and assessments are not family-directed, it is well worth the effort and resources to ensure that they are.

The authors hope that the lessons learned from this report will be taken into consideration by those who plan policies and who provides services to young children with disabilities and their families. Families have taught us that the principles articulated throughout this paper make a very important difference in the success of early intervention services.

The references and resources listed in the following sections represent a fragment of the materials that are available concerning processes related to family-directed child evaluation and assessment. They illustrate the wealth of resources available from the projects which participated in the development of this paper, as well as the rich array of projects supported by the Early Education Program for Children with Disabilities.

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Resources From Participating EEPCD Projects

ACTT Outreach: Activating Children Through Technology

Patricia Hutinger, Carol Schneider and Linda Robinson
Macomb Projects
Western Illinois University
27 Horrabin Hall
Macomb, IL 61455
(309) 298-1634
Fax: (309) 298-2305

Products:

Technology Team Assessment Process ($69.95)

Other resources on the use of technology.

Product list available on request.

The AEPS Linked System of Assessment, Intervention, and Evaluation for Early Intervention

Diane Bricker
Center on Human Development
University of Oregon
901 E. 18th Street
Eugene, OR 97403
(503) 346-0807
Fax: (503) 346-5639

Products:

AEPS for Infants and Children (2-volume set; $88)

Volume 1: *AEPS Measurement for Birth to Three Years.* (1992; $39)

Volume 2: *AEPS Curriculum for Birth to Three Years.* (1992; $59)

AEPS Data Recording Forms, Birth to Three Years. (Package of 10; $21)

AEPS Family Report, Birth to Three Years. (Package of 10; $15)

AEPS Family Interest Survey, Birth to Three Years. (Package of 30; $10)

AEPS Test Three to Six Years (Experimental Edition 2). ($40)

AEPS Family Report Three to Six Years. ($10)

Product list available on request.

Family Enablement Project at the Family, Infant, and Preschool Project (FIPP)

Angela G. Deal
Family, Infant and Preschool Program
Western Carolina Center
300 Enola Road
Morganton, NC 28655
(704) 433-2611
Fax: (704) 438-6457

Products:

Product list available on request.

Medically Fragile Inservice for Related Services Team (M-FIRST)

Pat Haley (Coordinator)
CDRC-Oregon Health Sciences University
P.O. Box 574
Portland, OR 97207-0574
(503) 494-8095 or 2794
(503) 494-6868
and
Janet Valluzzi (Coordinator)
CDMRC-University of Washington
CTU, WJ-10
Seattle, WA 98195
(206) 543-7403 or 685-1350
Fax: (206) 543-5771
Internet: valluzzi@u.washington.edu

Products:

Product list available on request.

NICU Follow-Through Project

Rodd Hedlund
Experimental Education Unit, WJ-10
University of Washington
Seattle, WA 98195
(206) 543-0925
Fax: (206) 543-8480

Products:

Infant Behavioral Assessment (IBA). Hedlund and Tatarka. (1988).

IBA Training Manual. (1991).

IBA Slide and Video Presentation.

The Synactive Model Slide and Video Presentation.

The Interactional Protocol.

Goal Attainment Scale.

Product list is available only to current or prior project trainees.

Project Continuity Outreach

Barbara Jackson and Joanie Dinsmore
Meyer Rehabilitation Institute
University of Nebraska Medical Center
600 South 42nd Street
Omaha, NE 68198-5450
(402) 559-5765
Fax: (402) 559-5737

Products:

A Case Management System for Infants with Chronic Illnesses and Developmental Disabilities. *Children's Health Care,* (1992). *21:4*, 224-232.

Product list available on request.

Project Dakota

Linda Kjerland
Dakota, Inc.
680 O'Neill Drive
Eagan, MN 55121
(612) 455-2335
Fax: (612) 455-8972

Products:

Product list available on request.

Project Vision

Lawrence Ingalls and Helen Hammond
Center on Developmental Disabilities
University of Idaho
129 West 3rd Street
Moscow, ID 83843
(208) 885-6605
Fax: (208) 885-9056

Products:

Delivering Sensitive Information. (a manual)

Planning Family Goals: A Systems Approach to the IFSP. (1992; $35.00)

Product list available on request.

Trans/Team Outreach

Corinne Garland
Williamsburg Area Child Development Resources
P.O. Box 299
Lightfoot, VA 23090-0299
(804) 565-0303
Fax: (804) 566-0144

Products:

Transdisciplinary Arena Assessment Process: A Resource for Teams (43-minute videotape and accompanying Viewing Guide; $149.95)

A Family-Centered Team Process for Assessment. (15-minute videotape; $59.95).

A Family-Centered Team Process for IFSP Development. (15-minute videotape; $59.95)

Understanding the Individualized Family Service Plan (IFSP): A Resource for Families. ($15.00; 26 or more copies, $9.95/each)

Product list available on request.

Resources Related To Technology

Valuable resources for early intervention programs are the consumer- and advocacy-oriented Alliance for Technology Access Projects and projects funded under the Technology Related Assistance for Individuals with Disabilities Act of 1988 (Tech Act), which are administered by the National Institute of Disabilities and Rehabiltiation Research (NIDRR) of the U.S. Department of Education. Most states have access to one or both of these kinds of projects. The national offices for these projects can provide a directory of projects and additional information about resources in each state; their addresses are listed below.

Alliance for Technology Access Projects

2173 E. Francisco Boulevard, Suite L
San Rafael, CA 94901
(415) 455-4575
and
1531 Dawn Drive
Louisville, KY 40216-1617
(502) 449-0654

Tech Act Projects

RESNA Technical Assistance Project
1101 Connecticut Avenue, NW,
Suite 700
Washington, DC 20036
(202) 857-1140 (voice/TDD)

Additional Readings

The following are selected resource materials that may be of interest to those who develop policy. We include them because they either were suggested by those we interviewed, or came to our attention serendipitously. This is by no means an exhaustive list.

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National Early Childhood Technical Assistance System
a program of the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill
137 E. Franklin Street, Suite 500
Chapel Hill, NC 27514
(919) 962-2001 (voice) • (919) 966-4041 (TDD)
Fax: (919) 966-6453
Internet: nectasta.nectas@mhs.unc.edu
World Wide Web: http://www.nectas.unc.edu/